healthwatch
Oxfordshire
Your voice on health and care services

Leaving hospital with medicine - Oxford University Hospitals NHS Foundation Trust

"For me everything went well, I got the medicines with instructions very clear"

"The patient medicines helpline sounds good, but I didn't know about it till now"

"It's not clear what to do if you have questions"

January 2023

Contents

1. Acknowledgements

With thanks to all who took part in this survey, and in particular those who came forward to share their stories with us in more depth.

Thanks to Oxford University Hospitals NHS Trusts Patient Experience, pharmacy and discharge teams for their support

2. Executive Summary

In early 2022, Healthwatch Oxfordshire was asked to help Oxford University Hospitals NHS Foundation Trust (OUH) gain insight into patient experience of the **Patient Medicines Helpline**.

People leaving hospital with prescribed medicines following treatment may need additional information and support. It is recognised that "hospital discharge may be a confusing and / or risky period for patients who have recently experienced changes to their medicines" and when handled poorly, may lead to complications or readmissions (Williams et al. 2020:1).

Oxford University Hospitals NHS Foundation Trust has clear processes and procedures in place for discharge of patients from its hospitals following treatment. A leaflet given to patients on admission explains all aspects of the discharge process. This includes what to expect of the "discharge journey with medications", outlining how support will be given, and who will be involved.

The OUH Patient Medicines Helpline provides support – via email and phone - from a pharmacist to patients leaving hospital with medicines. It enables them to ask questions or alleviate any worries they may have about their medicines once they have got home.

A survey held between July and end of September gave people an opportunity to comment on experience of discharge from hospital with medicines, as well as of using the Helpline.

In total **we heard from 113 people** - 105 people via the survey and 8 people face-to-face at the discharge lounge in the John Radcliffe Hospital. 9 people kindly came forward to share their **stories in depth,** illustrating the journeys people took. Some of these stories are included at the end of this report, and can also be found at www.healthwatchoxfordshire.co.uk/have-your-say/your-stories/

- 38 respondents had been discharged "more than six months ago", 27 "between one and six months", whereas **40 had been discharged between "less than 1 week to 4 weeks"**
- The majority **gave feedback on their stay in the John Radcliffe (61 respondents)**, in addition to the Nuffield (19), Churchill (15) and Horton (8). They represented stays in a wide range of settings including maternity, cardiology, trauma, accident and emergency, surgical, respiratory, oncology

  - **Ethnicity** 86% White British, 1% Asian/Asian British Pakistani, 1% Black/ Black British/ African, 2% Mixed/Multiple Ethnic, 3% White other, 1% White Irish, and 3% “prefer not to say”
  - Of these people identified their **gender**: 63% women, 32% men, and 4% “prefer not to say”
- **Age:** of 93 people who told us their age group:
    - 1 was 18-24
    - 16 were 25-49
    - 14 were 50-64
    - 46 were 65-79
    - And 3 were 80+

3. Key findings

Information about medicines

- We heard much praise of the support, care and consideration given by all NHS staff

  “brilliant, couldn’t fault, wonderful care, thankyou!”

- Of 105 respondents who completed our online survey, the **majority indicated that they had been given clear, thorough information about their medicines**, and that health professionals had taken time to explain
- 75 respondents agreed they “felt confident about going home with their medicines”, and 72 agreed they had been given “all the information I needed”

  “I was given all the support and information I needed regarding my medicines and felt confident about going home”

Some indicated they were **less confident and needed more information** about their medicines

- 19 agreed they felt “worried about making mistakes” once home with their medicines
- 23 agreed they “wanted more support and information” about their medicines once home

  “No discussion on how to administer!”

A key finding was that few respondents had heard of the patient medicines helpline:

- Of the 105 respondents we heard from via online survey, **only 10 had heard about the Patient Medicines Helpline, indicating a significant gap in awareness of and communication about this support**

  > *"The patient medicines helpline on this list sounds good, but I didn't know about it until now"*

- The majority (65) told us they would call on their GP, and 16 would contact a Community Pharmacy if they needed more information about their medicines once home

In addition, we identified cross cutting themes:

- **Clear and timely communication about medicines**
  - Patients valued time taken by health professionals to explain clearly and answer questions or concerns about medicines. Timing of this was important – patients wanted information well before discharge and when not in pain or post recovery. Involving family or friends in medicines information was seen as important by some
  - Whilst information about medicines was given on a discharge letter and medicines pack, a number of patients commented that instructions could be more 'patient friendly' written in clear language and relating to real life routines

- **Discharge waiting times**
  - Numerous comments focused on **frustrations about the delay in discharge and in waiting for medicines** from the pharmacy once ready to leave hospital - some waiting for almost the whole day
  - This gave a sense of patients being left not knowing what was happening, with both them and family members being unable to anticipate or plan

  "The wait for medication from the hospital pharmacy is intolerable. In my case it was all day"

- **Communication and interface with the wider system**
  - We heard about different aspects of communication and interface between patient and other health professionals once they had left hospital. Where they should turn was not always clear to the patient, and this could be stressful for patients

"I have no ideas how to go about obtaining more painkillers – John Radcliffe or GP?? Repeat Prescription?"

- **Interpreting**
  - Whilst only one comment, it is of importance to note that that an interpreter was not offered to a patient who needed one:

"I have never been offered a sign language interpreter when I am in hospital"

4. Recommendations

The following recommendations are made to **Oxford University Hospitals NHS Foundation Trust**.

- Review all aspects of promotion and communication about the Patient Medicine Helpline (posters, website, leaflets and spoken communication as well as focus on reach and targeting) for patients to increase awareness of offer and uptake of this support available
- Gain input of hospital patient group to help improve the written communication and instructions for patients about medicines taken home to ensure they are "*presented in a more human friendly way, a more patient friendly way"*
- Review and improve discharge process within hospital including understanding where blockages occur, including timing, and dispensing medicines and communication between ward and pharmacy and discharge lounge so as to reduce waiting times for patients. Improve communication around waiting times to ensure patients feel less powerless and are informed about what is happening during their wait
- Review and ensure patients have clear communication about follow up prescriptions and where to turn once left hospital, including with GP, community pharmacy

In addition, this report includes learning for the wider system about communication and joined up work. It will be shared with Oxfordshire's Primary Care Networks (PCN), Pharmacy Thames Valley, and Buckinghamshire, Oxfordshire and Berkshire Integrated Care Board (BOB ICB).

5. Background

Management of medicines with a patient involves a "systems wide" approach, reliant on coordinated, effective and timely communication. It involves joined up work bringing patients and carers together with health professionals across the interface of secondary care (e.g. hospitals) primary care (e.g. GPs, Primary Care Networks), community pharmacies, and others, such as pharmacy sub-contractors.

People leaving hospital with prescribed medicines following treatment may need additional information and support. "Around 60% of patients have three or more changes made to their medicines during a hospital stay and only one in ten elderly patients return home from hospital taking exactly the same medication as when they were admitted" (https://www.oxfordahsn.org/our-work/care-homes/safe-transfer-of-care-around-medicines/). It is recognised that "hospital discharge may be a confusing and / or risky period for patients who have recently experienced changes to their medicines" and when handled poorly, may lead to complications or readmissions (Williams et al. 2020:1).

Oxford University Hospitals NHS Trust has clear processes and procedures in place for discharge of patients from its hospitals following treatment. A leaflet given to patients on admission explains all aspects of the discharge process. This includes what to expect of the "discharge journey with medications", outlining how support will be given, and who will be involved, as follows:

Oxford University Hospitals NHS
NHS Foundation Trust

PLANNING
YOUR DISCHARGE

MAKING PREPARATIONS
FOR YOUR RETURN HOME

My to do list
☑ arrange transport
☑ remember house keys
☑ switch on the heating
☑ groceries

The discharge journey with medicines

We ask all patients to bring their medicines from home into hospital. This is so we can check what medicines you were taking prior to your admission.

We will use your medicines where appropriate during your stay and return them to you at discharge, along with any newly prescribed medicines from the hospital pharmacy. Let the pharmacist know if you already have supplies of your medicine at home.

We will give you a *Green Medicines Bag* on discharge to keep your medicines in. You will be also be given a Discharge Letter detailing any medicines you are going home with. (This bag is useful as a reminder to bring in your medicines should you need to come into hospital in the future.)

We will explain your medicines before discharge. There are written instructions on the packaging which also includes a manufacturer's information leaflet. There are also details about your medicines in the discharge letter.

If you require more information about your medicines before you leave hospital, ask the hospital pharmacist who visits your ward, or your nurse or doctor.

When you are back home and your medicines are running low, you should contact your GP and ask them to prescribe the medicines you need to take. Please only order supplies of the medicines you need.

Your local pharmacy can help you understand and manage your medication once you have left hospital. If you would like your local pharmacy to do this, please tell the hospital pharmacist, before you are discharged, and they will organise this for you. (This is known as *Transfer of Care* service.)

Source see: https://www.ouh.nhs.uk/patient-guide/leaflets/files/13187planning.pdf

Before discharge, a health professional – nurse, doctor, care assistant or ward pharmacist, will take time to explain to the patient about their medications and how these should be taken. These are dispensed via the hospital pharmacy. A patient may then wait on the ward or in the discharge lounge for medicines to arrive (or for other aspects of discharge e.g. transport or care) to fall into place before they return home.

Both the NHS and individual hospital trusts offer additional support for patients around medication (For more detail, see Appendix 7). On return home following a hospital stay patients may be offered in-house support via:

- A **Patient Medicines Helpline** – dedicated phone line open to all patients leaving hospital to contact hospital pharmacist for follow up support and advice on taking their medicines. **Oxford University Hospitals NHS Trust** offers a Patient Medical Helpline, five days a week (https://www.ouh.nhs.uk/services/departments/pharmacy/helpline.aspx).

Or, where eligible, patients *may* be referred for additional support via services commissioned from Community Pharmacies:

- **Discharge Medicines Service (DMS)** (from 2021) – referral from hospital where more complex cases are referred direct to a community pharmacy for support with medications (https://www.england.nhs.uk/primary-care/pharmacy/nhs-discharge-medicines-service/)
- **New Medicines Service (NMS)**– referring patients who are taking medicines for the first time for a diagnosed long-term condition to a community pharmacist (https://www.nhs.uk/nhs-services/prescriptions-and-pharmacies/pharmacies/new-medicine-service-nms/) (this is not specifically related to hospital discharge)

The GP, or GP based pharmacist will provide regular and ongoing medication review once a patient is home and needs follow up.

6. Research scope and methods

This research was undertaken following a request of the Oxford University Hospitals NHS Trust pharmacy team. They wanted to hear from patients about their experience of using the Patient Medicines Helpline, and to identify any areas for improvement or change. They had identified strengths of the service, but noted that it is “reactive” with limited time available for learning and improvement. They asked Healthwatch Oxfordshire as an independent watchdog to find out about patients’ experiences.

An online survey (Smart Survey ™) was designed, drawing on guidance from both The UK Medicines Information Patient helpline audit standards: https://www.sps.nhs.uk/wp-content/uploads/2017/01/MedicinesHelplineStandardsvn3_2.pdf and "*Guide to implementing a helpline for hospital patients and user survey*": https://www.sps.nhs.uk/wp-content/uploads/2017/01/ImplementingaMedicinesHelplinevn14.pdf

The survey covered aspects of support, information and follow up for patients around receiving medication to take home following hospital treatment, as well as experience of support via the Patient Medicines Helpline.

To reach patients, Healthwatch Oxfordshire relied on support of Oxford University Hospitals NHS Trust. Survey posters and information leaflets – with an online link - were printed and placed across John Radcliffe, Horton, Nuffield Orthopaedic and Churchill sites in waiting rooms, hospital pharmacy, discharge lounge and direct into patient discharge medicines packs. Additional printed surveys were provided in the hospitals along with "Freepost" envelopes, and a "post box" for collection. Translated copies were offered to be provided on request.

To try and reach people who might not fill in surveys, and those from seldom heard communities, Healthwatch Oxfordshire spoke to people face-to-face at the John Radcliffe Hospital during outreach, plus a focused visit to the discharge lounge. This gave the opportunity to speak to patients and see the process in "real time" around discharge and medications whilst waiting to leave hospital.

The survey was widely promoted via social media, email, and on websites of both OUHT and Healthwatch Oxfordshire, to reach wider networks across the county. Posters and links were provided to Patient Participation Groups, voluntary groups, GP surgeries, and community newsletters. Age UK Oxfordshire, who provide commissioned hospital discharge support to patients, were also given posters.

Discharged from the
NOC, JR, Horton or Churchill
hospitals with medication?

Did you get the support and
information you needed?

Tell us about your experience by completing
our anonymous survey at
www.smartsurvey.co.uk/s/medicinesathome
or by scanning the QR code below

The survey closes on 30th September 2022

For help completing the survey, or to request a
paper or translated copy, call 01865 520520

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We explored how to access to people directly as they contacted the Patient Medicines Helpline, but issues of GDPR, hospital pharmacy capacity, time, and staff pressures within a very busy service and due to Covid meant that this was not possible.

We offered people the opportunity to tell us about their experience in more depth, following this up with interviews online via Zoom, Teams or on the phone.

Survey responses were analysed to draw out key themes and issues, and this report is written to highlight the voices of those who responded. Some anonymised in-depth stories are also included to give greater insight into patient journeys within the system.

In retrospect, an expectation of focus on aspects of experience of the medicines helpline has given less insight into the wider systems involved beyond the hospital. However, respondents did tell us about interaction with others – community pharmacies, GPs, and other sources of support such as NHS 111. In future a wider look at the systems wide pathways people take would be of use, including the pathways of Discharge for Medicines, including community pharmacy and GP roles.

7. Results: Who we heard from

Who we heard from

We heard from **113 people**. 105 people via the online survey, 9 of whom shared their **stories in depth** via follow up interviews. We spoke to a further 8 people face-to-face at the John Radcliffe hospital.

Data found in the graphs below and in the Appendix relate to the online survey responses. Comments and insight from face-to-face conversations are included in the narrative themes. In depth stories are found at the end of the report.

Demographics of 105 online survey respondents (**93 answered this question**) indicated:

- **Ethnicity** 86% White British, 1% Asian/Asian British Pakistani, 1% Black/ Black British/ African, 2% Mixed/Multiple Ethnic, 3% White other, 1% White Irish, and 3% “prefer not to say”
- Of these people identified their **gender**: 63% women, 32% men, and 4% “prefer not to say”
- **Age:** 1% 18-24, 17% 25-49, 15% 50-64, 49% 65-79, 13% 80+, 3% “prefer not to say”

Respondents told us about their stay in hospital and interactions around medicines.

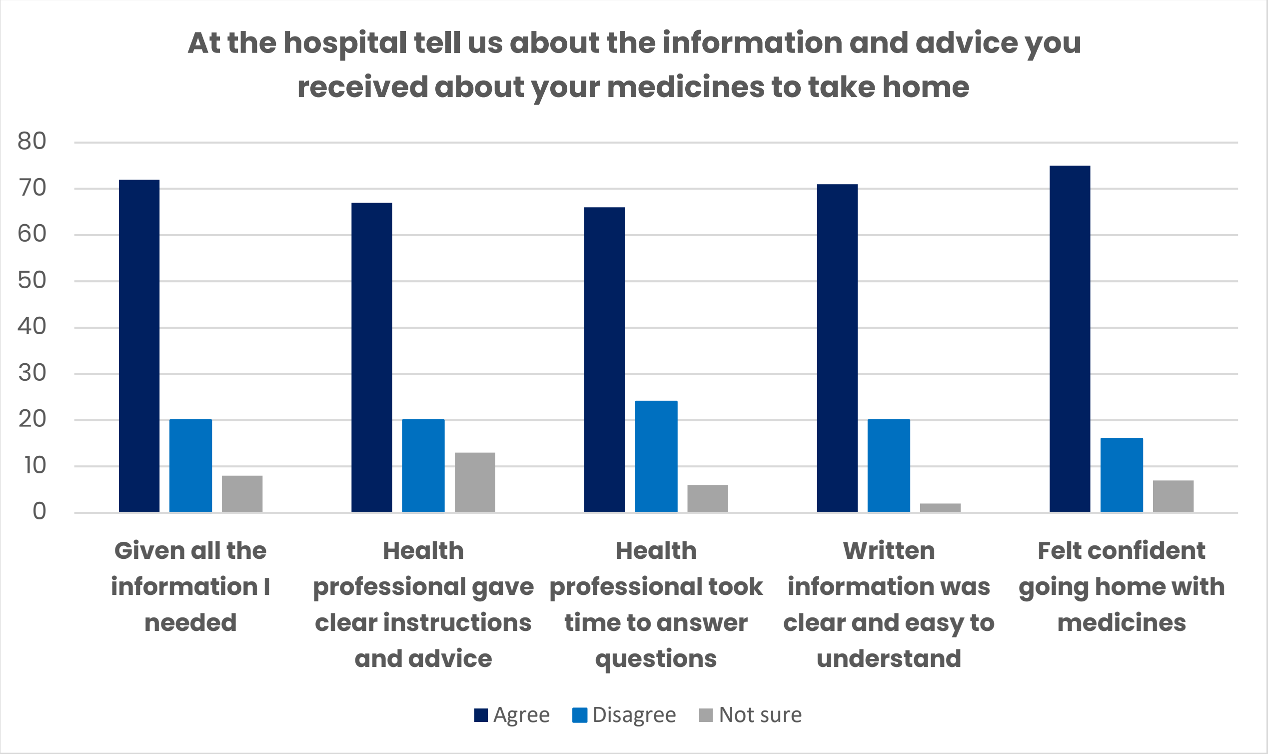
- The majority, **(61 respondents) gave feedback on their stay in the John Radcliffe**, 19 at the Nuffield, Churchill (15) and Horton (8). They represented stays in a wide range of settings including maternity, cardio, trauma, accident and emergency, surgical, respiratory and oncology
- 38 respondents had been discharged “more than six months ago”, 27 “between one and six months”, whereas **40 had been discharged between “less than 1 week to 4 weeks”**
- When asked **which health professional had given them advice** and information about medicines; **59 told us a nurse**, doctor (34), pharmacist (15), and a health care assistant (9) had given information
- **9 told us they had been given “no information”** and 8 were “not sure” if they had been given advice and information about their medicines.

8. Results: overview of what we heard

People told us about their experiences of the journey from hospital to home with medicines.

- **Before leaving hospital**

We asked people to tell us about the quality and clarity of information and advice given at hospital on medicines to take home.



(105 respondents. Response number indicated)

Of 105 respondents, the majority agreed with the statements, indicating that they had been given clear, thorough information, and that health professionals had taken time to explain.

75 respondents agreed they "felt confident about going home with their medicines", and 72 agreed they had been given "all the information I needed".

These respondents praised the staff, and valued kind, professional and compassionate interactions, where time was taken to explain medicines clearly

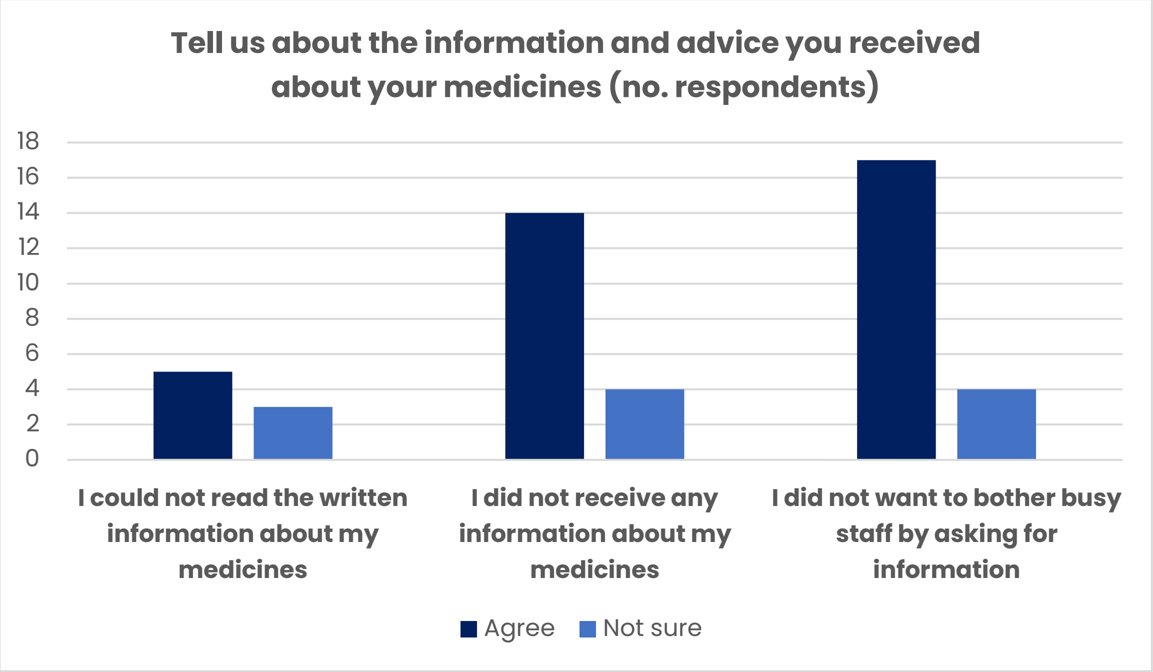
> *"the doctors and nurses were all excellent in their information and advice"*
>
> *"excellent information and time, despite busy unit"*

> *"nothing was too much trouble"*
>
> *"I was given all the support and information I needed regarding my medicines and felt confident about going home"*
>
> *"I was not given written information, but staff at the hospital took time to explain things and I made notes. I asked many questions, and they were patient with the answers"*
>
> *"meticulous attention to detail by two pharmacists"*
>
> *"the consultant gave me the medication explaining exactly how to take it"*

Some ***disagreed*** with the statements:

- 20 disagreed with statements that they had the "information and advice needed", and that "advice was clear"
- 24 disagreed that "the health professional took time to explain"
- And 16 disagreed with the statement "I felt confident about going home with my medicines"

In addition, a small number of respondents told us they had not received adequate information about their medicines.



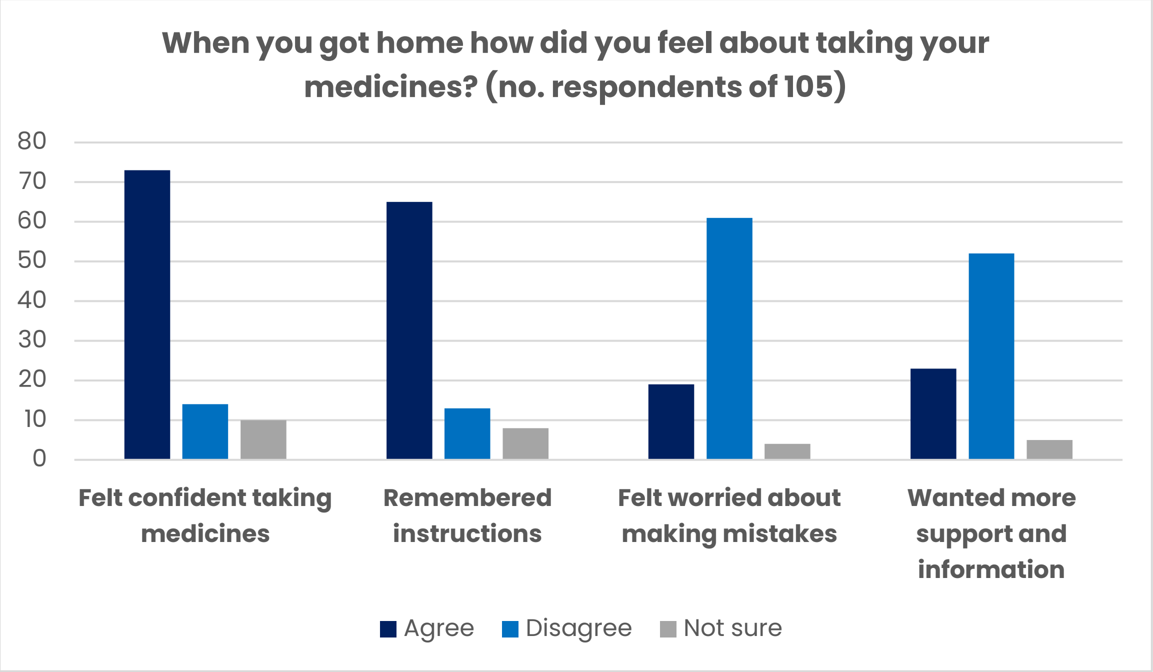
- 5 agreed with the statement "I could not read the written information" and 3 were "not sure" they could
- 14 "did not receive any information about my medicines" and 4 were "not sure" they had
- 17 indicated "I did not want to bother busy staff by asking for information" and 4 were "not sure".

> *"Did not have time to explain the medication and how to use. Also then had to search for the information myself"*
>
> *"No discussion on how to administer!"*
>
> *"I was concerned about side effects, but no-one would discuss with me"*
>
> *"information was rather rushed"*
>
> *"It felt a little rushed, but it is a busy ward…"*

- **Getting home**

We asked people to tell us about their experiences of their medicines once they reached home: did they remember, feel confident and clear about the instructions they had been given about their medicines and did they have any worries?

When you got home from hospital, how did you feel about taking your medicines?



- Of 105 respondents, 73 agreed they were "confident in taking my medicines", 14 disagreed
- 65 agreed they "remembered the instructions I had been given", 13 disagreed

> *"I was well informed about the medication and confident in the explanation and advice given. I fully understood the reason for the drugs and the importance of them"*
>
> *"The pharmacist provided me with clear tabulation of each drug, its strength, quantity and times of dosage. There was a field on the spreadsheet that explained exactly what each drug was for…very good document"*

In addition, some were less confident:

- 19 agreed they felt “worried about making mistakes” with their medicines
- 23 agreed they “wanted more support and information” about their medicines once home
- 24 people told us they were “concerned about side effects”
- 8 told us they had “not got any information about their medicines”
- And 9 told us they were “uncertain about what my medicines were for”

> *“I was a little alarmed at being told I needed to have anti-coagulant injections after discharge…I didn’t think I could administer them myself!”*

> *“Oh, my goodness, I knew I had to sit down and read this page and a half of medications, because it was about to be dinner time and I knew I needed to take some tablets and I didn’t know which ones it was. In the grand scheme of things, it was fine, but it was quite overwhelming”* (See Patient Story 5)

➢ Timing of support and advice

We asked people to tell us what the best time to have information and advice about medicines to take home.

Of 95 responses, 83 indicated the best time for information and advice would be “before leaving hospital” and only 3 “after leaving hospital”. People wanted to be given information in a timely fashion and before they were involved in the rush of getting home.

> *“Need time to process the information and discuss any necessary queries before leaving”*

> *“Ideally for me, well before discharge…there is a lot going on. I was on heavy pain relief so the mind is not totally clear. That extra time would allow the brain to work and it is better to raise the question before discharge than think of them when you get home”*

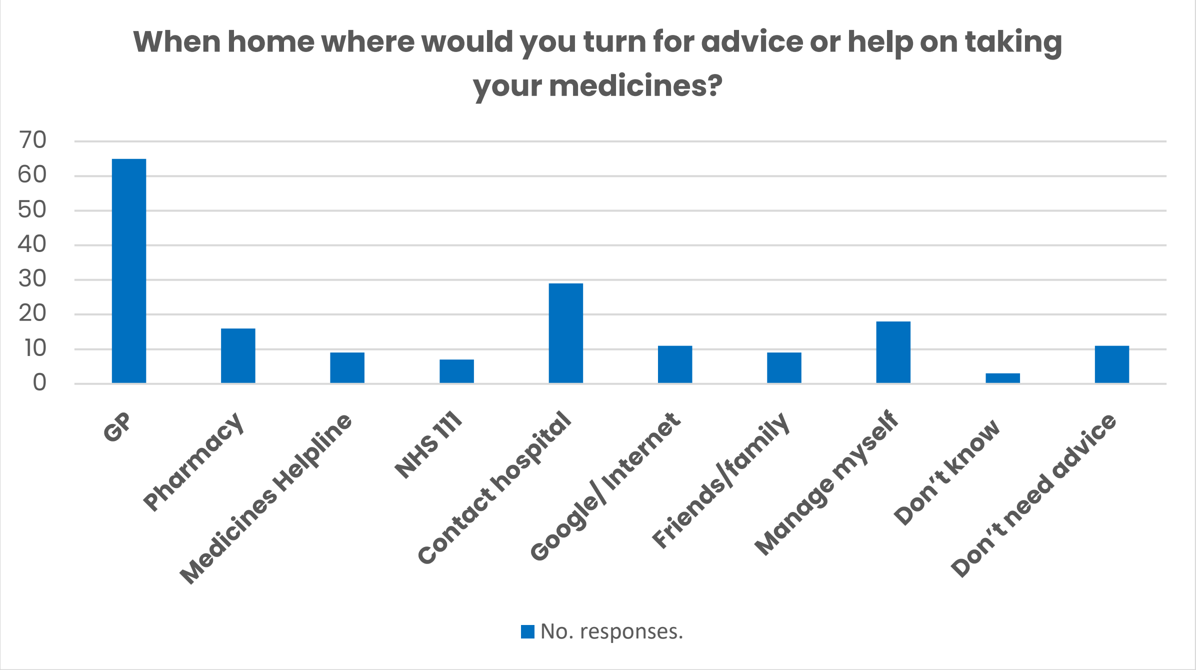
> *“The advice I was given before being discharged was great. However, as things change at home and other worries arise, it’s helpful to be able to consult further sometimes”*

> *“It was good to have information to take home, but it might have been nice to have a phone call the next day to see if I was comfortable with everything”*

> *“I think the pre op Assessment Clinic is the place to give people information. Because, you know, your, your head is in the right place there. And if you're given some basic information there, and told to keep it until afterwards, if you have any questions, these will be your contact numbers. I think that that's a good time to because, I found my pre op assessment clear”*

- **Seeking advice and support once home**

We asked people where they would turn once home if they felt they needed more advice or help about their medicines.



(105 respondents)

- The majority (65) would call on their GP, and 16 would contact a Community Pharmacy
- Some comments indicated that people were uncertain as to where to turn, noting various routes
- And … **only 9 noted they would use the OUHT Medicines Helpline**

"It's not clear what to do if you have questions"

"Very hard to get in touch with a doctor"

"I forgot once I got home"

"Our GP had shut up shop by the time we got home, and NHS 111 refused to give us any advice whatsoever"

"I can contact the specialist nurses at the John Radcliffe, or take my questions to the consultant"

"Before I was discharged by the midwives, they were quite helpful with follow up. It was harder after I was discharged"

- **Awareness of the Patient Medicines Helpline**

We asked people to tell us about their experience of using the Patient Medicines Helpline. Results were surprising.

Of 105 respondents, only 10 had heard of the helpline, indicating a significant gap in awareness of and communication about this support.

Of those who had heard about the helpline:

- 2 had heard from a health professional
- 1 had found information on their discharge notes (the number is in small print at the end of discharge notes)
- 1 found information on the internet
- 1 was told by their GP

> *"The patient medicines helpline on this list sounds good, but I didn't know about it until now"*
>
> *"Did not know about the OUH patient medicines helpline. If I was told, I forgot, but it would be a very useful number to have"*
>
> *"I didn't know the medicines helpline existed until I saw this survey….looking now at my notes …on the medicines discharge list…page 2, page 3, right at the end it says, "if you have any questions please ring the patient helpline" there we go - I just didn't see it … looking at it now, it runs Monday to Friday, which is great, and I understand staffing, but I got home on a weekend evening, so some questions would have waited till the helpline and some wouldn't … I guess.*
>
> *It would have been really helpful to be able to ring the medicines helpline and say, "I have got all these medications which have large, alarming warnings about addiction (opiates for pain), how scared should I be?" (See Patient Story 5)*
>
> *"KNOWING about the patient advice line would make a big difference. I do not remember getting this information BUT if it was slipped in as paperwork with the discharge pack I missed it. BIG BOLD TYPE so it cannot be missed would help"*

As a result of limited knowledge of the medicines helpline, little information was given on use of or effectiveness support. One person who had used the helpline indicated that support was "good", the times available were convenient, with quick response. Not all staff we spoke to at the discharge lounge were aware of the helpline, or that they could or should be promoting it. Those who did know about it indicated that they promote it selectively to patients based on assessment of individual need.

9. Results: cross cutting themes

The following section briefly draws out cross cutting themes that arose from people's comments about discharge with medicines from hospital. The **patient stories** at the end of the report illustrate in more depth some of the themes, as well as bringing to life the overall experiences and journey people took.

- **Clarity of information and communication**
  (See also Patient Stories 1, 3,5)

Patients commented that clear communication and information about medicines was essential, and timing important. Being told information when in pain or post op was seen as a barrier to understanding, and could result in confusion once home.

> *"What people (could) do was repeat what I'd said. Yeah. Because it goes in better, you know, if you say to somebody, "you can take these four times a day, and you can take these if you want to. And you could take these", you know, it just goes ("blah blah blah"), you're in a lot of pain. And then when you get home and start to read it, you know, if somebody else is looking after you they try to take over, you know, my daughter was putting them ready for me"* (Patient Story 1).
>
> *"If complicated I would also like it written down as it's easy to forget when you are leaving hospital"*

Whilst information about medicines was given on a discharge letter and medicines pack, a number of patients made comments that instructions could also include more 'patient friendly' information written in clear language and relating to real life routines…

> *"Need all information written down clearly – not on a tiny prescription label or sent a week later to my GP in a discharge letter…"*
>
> *"It was quite overwhelming, to actually just do all of those things and yes, the thought of somebody more vulnerable having to do it, my goodness if I was feeling fragile enough, at that point it must be so much worse for other people. I just thought "what I need is a list which says "take these at breakfast" "take these at lunch" I wrote myself a list and I put it on my phone, so I could copy and paste it for each day and cross off the ones I*

> *had taken, but yes, they could have given me that list in a more helpful way" (Patient story 5)*
>
> *"A fact sheet would have helped, I don't think they had anything like that. It would have helped I think if there was if somebody had come out and said, "that's what it recommended and just read that and it tells you all about it"*
>
> *"And it just wasn't organised - it was organised like for a medical person who might need to know what you were taking, and it's really good to have that, as when the pharmacist at the GP surgery wanted to do a medication review, I had a list … but actually for a human being taking these, what you really need to know is "at breakfast time take these ones and at lunchtime take those ones". I like to organise data, and this data could have been presented in a more human friendly way, a more patient friendly way…." (Patient story 5)*

- **Offer of interpreter and D/deaf awareness:**

One D/deaf patient commented that they had never been offered support with communication and interpreting whilst within the hospital:

> *"I am profoundly deaf. It is difficult for me to have conversations with pharmacists behind a plastic screen, and medical staff wearing masks. I have never been offered a sign language interpreter when I am in hospital my parents have to come in and stay with me (even though I'm an adult) so that they can make sure I don't miss any important information or decisions. It means I have no privacy about my condition or my treatment. I feel JR need to improve their communications with deaf patients"*

Anecdotally we were told that most making use of the Patient Medicines Helpline service speak fluent English. Staff spoken to were "not aware" of take up of interpreting offer to date, commenting "occasionally family members have interpreted".

- **Waiting time for medicines and discharge**
  (See also Patient Story 4)

Numerous comments focused on frustrations about the delay in discharge and in waiting for medicines from the pharmacy once ready to leave hospital -some waiting for almost the whole day. This gave a sense of patients being left not knowing what was happening, with both them and family members being unable to anticipate or plan.

Improvements to this process including timing, waiting time and dispensing medicines, as well as better communication around waiting would help some feel less powerless, and be able to plan.

> *"The wait for medication from the hospital pharmacy is intolerable. In my case it was all day"*
>
> *"Waited approximately five hours for medication, this could have led to bed blocking"*
>
> *"I waited for 7 hours for the pharmacy to get my medication ready. When I was finally told I could go and collect them the pharmacist then said I needed a member of staff from the ward to actually hand them to me. This meant a trip back up to the ward and then down again to get the medicine…a total lack of communication and unnecessary additional work for already overworked nursing staff"*
> *"It was the slowness of supply to get me discharged that was the problem. From 10 a.m. they then managed to get the medicines by 6 p.m."*
>
> *"In my experience, the only downside is if you're on any medication that requires you to have a prescription for some more, if it's a new medication, you know, apart from the one I'm going to go on to, you can be sat about literally for hours waiting for it to come up from the main pharmacy. The number of patients who were in, were literally waiting hours - when I say hours - like five or six hours just for the medication to come up. And they won't allow you to go down and collect it yourself. You know, so that can be very frustrating" (Patient Story 4).*
>
> *"The time taken to wait for TTO's when leaving the ward is ridiculous. I routinely need to wait 5 hours or more before they are dispensed, and even then there is always some query or issue that needs sorting out"*
>
> *"Ready to be discharged before breakfast but it took until 5.30 p.m. for the medication to be available…could have released the room long before and I would have been out of hospital making space for the next patient!"*

> *"I had to wait six hours for my medication only to be told they would deliver it the next day. Was only told at discharge point it's the same meds I take on a day to day basis"*
>
> *"I think this is disgraceful way to treat any patient…this is something that needs to be addressed as every hospital stay it has always been the same"*
>
> *"the problem I encountered was at the hospital pharmacy … after handing in the prescription I was told it wouldn't be ready for an hour. I got my transport home and an hour later my partner came to collect my prescription, only to be told they did not have any painkillers, with their delivery the next day … as my pain levels started to raise, I had to re-submit myself to Accident and Emergency. Pharmacy was 1 out of 10"*
>
> *"long wait for medication and lack of communication between pharmacy and ward"*

During the visit to the discharge lounge at the John Radcliffe, we were able to see the process in action. Staff were highly professional, caring and attentive, and spent time with patients and their families to carefully explain the medications they had been given. Staff told us that they double check patients have received the right information, and check against discharge letters, and liaise closely with pharmacists and doctors.

Delays in the system contributing to waiting times for medicines included inter-departmental communication, scripts not being signed off and passed on from ward, and workload of dispensing pharmacy, and occasional failure of the 'robot' which packs medicines.

- **Relying on friends or family vs. living alone**
  (See also Patient Story 1 and 5)

One theme that arose was both the reliance patients had on family members and friends to help with their medicines – interpreting information and listening, dispensing them, and collecting both from hospital or pharmacists. This support was particularly important for patients who were not thinking clearly post op or were in pain. Involvement of family or friends was seen as important to patients.

> *"To have a friend or family member in the room to help me process the information"*

> *“I rely on my wife to help with my medication”*
>
> *“My mum and my sister live with me so they could help if needed”*
>
> *“I was worried as my daughter was giving me the meds she got confused and had to check. I was in a lot of pain”*

However, those without that support or who live alone found arriving home with medicine could be confusing and more challenging. People also noted concerns about how patients with dementia or other factors impinging on absorption of information would manage. Here, the helpline would be especially useful.

> *“The nurse suggested that I could go home in the morning and send a friend back in the afternoon to collect my medicine. As I live on my own and relying on kind neighbours to collect me this was totally out of the question”*
>
> *“I live on my own which feels a little bit relevant, in that (in my job), I am good at reading and processing information, switched on, good at looking after myself -but there wasn’t someone who could organise my medication for me (when I got home). So part of my thought was “I am quite well equipped to deal with this sort of stuff”, I am less phased by this than some people might be, and other people might be less sure, and “if I am finding it difficult, goodness me! how much harder must it be for people who are in a more vulnerable situation?” (Patient story 5)*

- **Follow up medication and interface across hospital, health professionals: GPs and pharmacists**
  (See also Patient Stories 2, 4)

We heard about different aspects of communication and interface between patient and other health professionals once they had left hospital. This was not always clear to the patient.

> **“***I was sent home on a Friday afternoon with only sufficient eye drops for 3 days and told to contact my GP for a continuing prescription. As it was a Friday this meant I had to go immediately to my GP on returning home to ensure staff knew I needed this medication as I would run out on Monday. This was very poor practice***”**

> *"So, when I was running out, I tried to order through the GP. The GP hadn't got round to scanning it in – apparently, they receive it as paper then have to scan it into their system. So, it seems crazy that it's all not linked, and they can't do electronically, but there we go. And when I spoke to them a week after I was discharged in hospital no one had scanned that in yet, so nobody had any idea what I was talking about on the phone. So, I then had to photograph my letter and email it to the GP surgery to, just an admin email address, for them to be able to see that letter quickly and forward it to a doctor to be able to issue these drugs"* (Patient Story 2)

> *"Once I ran out of medication I was told to reorder through my GP. This was very difficult as they were controlled drugs and the GP was very reluctant to help it felt like. Also the local pharmacies could not get hold of the medication. It would have been better if I could have had a prescription to collect from the local hospital pharmacy instead"*

> *"I have no ideas how to go about obtaining more painkillers – John Radcliffe or GP?? Repeat Prescription?"*

> *"My prescription ran out of one drug and the Doctor told me I needed to continue taking it, when I contacted him by email, but did not tell me how to get a repeat prescription"*

> *"the whole hospital thing could be improved. My GP, when I could eventually get an appointment was very helpful but had to contact the hospital because she wasn't even sure what I should be taking and why"*

Patient Story 4 illustrates some of the wider complexities of system communication, for complex medicines provided by external provider… where communication between hospital and provider is not always clear

> *"I suppose it would have helped to say - there (needed to be) a bit more liaison and laying the ground rules down prior to discharge"* (Patient story 4)

> *"It is quite a specialist thing. And I guess this is, this is just an example of where the system can potentially, not break down, but not work as efficiently, when the pharmacy within the hospital is doing everything, they're, you know, they're in control of everything, but when they're relying on an outside company, you are just one of 1000s. And you know, the hospital has to issue a prescription to the exterior company - that can be problematic occasionally because pharmacist in the hospital may be*

> *under pressure, and they don’t always do it when they’re supposed to do it” (Patient Story 4).*

One patient comment illustrates the impact on family members of chasing up medicines post hospital discharge, as well as the short and long term stress this can cause.

> *“Of course, 5.30 was rush hour, so I waited a little while until after the rush hour as it was a late-night pharmacy, so I went to the pharmacy, took id, etc, and to say they should have received by e-transfer a prescription for my wife. They had the prescription, so the pharmacist went off to deal with it, and was gone some time, waiting, and then they came out and said “I haven’t got this drug” and I thought “oh god”, as I was really worried because I had been told this was urgent and that my wife’s life was at stake. They said they didn’t have the drug, so I was asking “would I be able to get it somewhere else?”, and they said they didn’t think so, or there would be problems because it was addressed to them”*

- **Complex medicines and side effects**
  (See also Patient stories 1, 4 and 5)

Some patients felt they needed more support with complex medicines such as injections and understanding dosage and use of opiates. Again, awareness of Patient Medicines Helpline would have provided support.

> *“Would have been good to show how to inject the anti-clot medicine in thigh”*
>
> *“I was really scared, I was really reluctant to take them, when the label said “may cause addiction” and I had heard about this, and it was really scary, so if there had been someone I could ring who could say “no, its fine, take it, a week is ok” that would have been great, very reassuring”* (Patient story 5)

- **Perceptions of waste**

A number of comments focused on perception of waste of medicine and cost to NHS. Better communication around this issue may be needed.

> *“Spoke to staff as given medicines I couldn’t take as am allergic to them, but was told to take it home anyway … I then had to take these tablets to the chemist to be destroyed”*
>
> *“The morphine, the doctor had withdrawn from my use 3 days prior…when I pointed this out … was told by the nurse “it has been delivered to you” …. she could not take it back, just to take it home”*

> *“I was given a ridiculous amount of painkillers, none of which I actually end up needing…it seemed such a waste”*

10. Patient stories

Story 1. Discharge during Covid.

Of course, it was influenced by the fact that COVID was rampant at the time. So, people weren’t so keen to come and see you before you went out. I understand (things) about medications that ordinary people might not. And my daughter got very anxious because they were strong tablets. And a lot of things I can’t take like … I’m not keen on painkillers, I would rather use meditation, but a knee operation is very painful.

And I felt anxious about the fact you only stay in one day anyway. So, you come out in a lot of pain, and need the medication. And my daughter didn’t know where to go to find out - the way it was written, because I was in so much pain, I couldn’t take it in - the way it was all written down. She got very confused. And of course, because it was COVID, I came out on my own. Normally, you would have somebody with you. I live alone. They just gave me the medications. It wasn’t as good as like, years ago when I had other operations. But it wasn’t explained properly.

They said, “of course, you have codeine”. I said, “I can’t take codeine because I get “x syndrome”” … The Doctor asked me “what is “x” syndrome?” And I said, “excuse me?!”, And they said, “I’m gonna go look that up”- Yes, you know, so I thought, “well, if you don’t know about that, it’s a bit worrying”, because it’s quite common knowledge.

I was very anxious, very anxious that I was going home on my own. So I didn’t take it in. Then when I got home, my daughter had all these tablets, and I couldn’t really explain it to her. I think she went to a pharmacist, and I think she asked her pharmacist for help, in the end, about what I could and what I couldn’t take. But of course, once she had gone home, yeah, I was on my own.

Of course, it was COVID. So it’s a different situation than normal, isn’t it? You would usually have somebody with you who could be listening as well as yourself. What people (could) do was repeat what I’d said. Yeah. Because it goes in better, you know, if you say to somebody, “you can take these four times a day, and you can take these if you want to. And you could take these”, you know, it just goes (“blah blah blah”), you’re in a lot of pain. And then when you get home and start to read it, you know, if somebody else is looking after you they try to take over, you know, my daughter was putting them ready for me. But I’ve got Dossett boxes - not everybody’s got those.

But somebody to make sure you know, before you go, because some people just say “yes”. So, to explain it clearly, because not everybody understands about medication. Make sure you can actually take the medication, because not everybody can. It’s not as easy as people think.

Okay, and allowing for dementia, of course. I mean, I was over 70 then, and we all have a degree of it, so to be a lot calmer and slower, and, you know, take the time. I’ve got several friends with early onset dementia, or haven’t got people, and I’ve got several friends who, in my opinion, take very strong, too many, too many tablets. Far too strong enough to take often, but you know, they get a little bit of pain and they take these strong tablets not knowing the side effects. And they’ve only got a little bit of pain, but they think if they stopped them, they’ll, you know, they’ll go in a lot of pain again.

At the moment, most people can only get phone appointments with their doctors. So, if you don’t know what you’re doing you carry on taking tablets, willy-nilly.

I do think I find pharmacists are more helpful than doctors now, If I want to know something, I usually go and ask a Pharmacist. Yes, because now with the state of the NHS, you phone the doctor - I phoned three weeks ago, and I’ve just had a phone appointment. I mean, that if I go in ask a Pharmacist something you get a sensible answer.

Story 2. Hospital / GP interface.

When I was in hospital, I was given all the same meds. I took all these medications during my stay in hospital. So, because I’d been in there for eight days, I mentally had an idea of what to expect. So, when it came to the day of discharge, the nurse came along with all the tablets prepared in two different bags. I was given two lots of medication, I had normal sort of antibiotics, and then controlled drugs as well.

The nurse made it clear that controlled drugs were in one bag, and normal drugs were in the other bag, they had to be kept separate. [Two nurses] came along and sat down next to me on the bed … they gave me the tablets, and actually got each tablet out of the bag, and explained what each tablet was and when I should take them. At the same time, they had printed off this six-page discharge letter telling me exactly what I'd had done. And on the back page of that it included every single medication, and how many times a day I should take it, what times as well.

So, as well as speaking through that with me, they also had it all written down. When I left, I could always refer to that. And they also wrote the ward telephone number. And they said, "if you've got any problems just call us on the ward directly, and we will help you with the medication". But I never needed to do that because they had explained it thoroughly when I was in hospital. And it wasn't a quick conversation, there was no rushing … they showed me everything. And then they had this letter they'd already prepared with it all written down for me.

So when I got home, I essentially just sorted it all out and had all this and I actually wrote my own little sort of chart, if you like of what I took when at what time, which sort of made it a bit more user friendly, but they'd written it all down for me so dead easy to essentially do, and take because they set it up really, really well. I got given 10 days-worth and then they said, "For your next order and you do that through the GP". But "that should be fine, because the GP should have received this same discharge letter", is what I was told at the time of leaving hospital.

So, when I was running out, I tried to order through the GP. The GP hadn't got round to scanning it in – apparently, they receive it as paper then have to scan it into their system. So, it seems crazy that it's all not linked, and they can't do electronically, but there we go. And when I spoke to them a week after I was discharged in hospital no one had scanned that in yet, so nobody had any idea what I was talking about on the phone. So, I then had to photograph my letter and email it to the GP surgery to, just an admin email address, for them to be able to see that letter quickly and forward it to a doctor to be able to issue these drugs.

Now, I often feel like everyone wants put their own stamp on everything. So the GP then phoned me and said, "Actually, this one medication, can we tweak it slightly to a tablet instead of a liquid?" Obviously, to me that I said, "Yeah, okay", you're sort of the specialist here. And to begin with, I didn’t find it as good. And the doctor at the hospital kind of said, "Oh, why have they done that?", but actually, long term, it wasn’t too much of a problem.

But when you’ve just been discharged from hospital, you don’t know what’s what. It’s not very helpful when people want to change things. And all I wanted was a repeat of what I already got, which is, they’ve got it all written down on a letter, they knew exactly what drug I needed, because it had all be written down. But they still wanted to, for some reason, change it. But at the time, it was a bit of a nuisance, because as I was still in quite a high pain threshold … it was quite painful, and this one medication really did help my pain. I had to go through a couple of weeks of really quite excruciating pain because they’d tweaked this medication. It worked in hospital … there was no reason to change it. When I started taking it, I realised that it wasn’t as effective.

I asked the surgeon I’m dealing with at the hospital, I queried this tablet with them because I had got to the stage where I needed painkillers to begin moving more. And it turned out what the GP prescribed was actually a slow-release painkiller instead of an *instant* release, which is what they’d [hospital] prescribed. The reason for giving the instant pain relief was that I could carry on with these exercises and do this stuff. So that was the reason why the hospital given me the liquid in the first place because it was instant, whereas what [GP] given was a slow-release version of it. But [hospital surgeon] didn’t realise they’d changed these tablets, nowhere on their notes did it say.

So, all these times I’ve been going to the surgeon they’d assumed I was on this other medication. But actually they had no idea until I told them that I was now taking these slow-release pain tablets. When I told them about it, they said, “I’m pretty sure that’s a slow release painkiller”, then went off to check it and came back said it is. They then said about actually having the liquid back, “I’d like you to go back to liquid”. But they can’t prescribe that, so, you know every time you have a hospital appointment they do a follow up letter, sent that and then I had to contact GP who then had to find that letter to read that line on the bottom, who then said, “Oh, yes, you can have that medication back”. Right. But they had to find the letter again and do it all that way.

If I had the person in front of me that I could talk to, I would say to them, “you need to think about your ways of using technology better, like these discharge letters need to be automatically uploaded instead of posted to people and having an admin person scan them in”. To me, that’s a waste of NHS money, paying someone to scan in letters from the hospital. It should be all connected, where they save it onto a system, and anyone can pick that up sort of straightaway. So I wouldn’t have to take photographs of it, I wouldn’t have to email them over. The GP could have read that straightaway. That’d be my first thing to say.

And my second thing would be if you’re discharging patients from hospital, and you tell them to go to their GP for their medication or for their repeats, it should be set up in such a way that I can just request that repeat with a dispensary at the doctors to work to get that medication. I don’t have to go through a GP to get them to make a prescription to link you in with them, it should all be linked in. Because it’s an unnecessary hassle, it’s a waste of GP’s time. Everyone’s saying how GPs are rammed at the minute, they’re booked up for months. To me, it’s a complete utter waste of their time. You’ve been discharged from a medical professional in the hospital giving this medication, yet, 10 days later, you’ve got to go through another medical professional. Bearing in mind you’ve been told by a medical professional that you can take these tablets, then go to another medical professional to then make a prescription for it. To me, that’s an utter waste of time.

Story 3. Communicating clearly.

What they come along with essentially, is a big bag full of a load of boxes, and a list. And the list is, from [my] memory, read through fairly quickly, in summary terms. And then they say, “Well, have you got somebody waiting to pick you up?”.

What would be much better would be for them to actually go through the medications, box by box, saying, this is this one, this is how you undo the packaging, and either it’s single use or it’s multiple use, and if it’s multiple use, this is how you do it. And just take you through each of the medications that you’re being issued. That would be that would be gold standard.

In the absence of that, it would be just having documentation that matches what you’re actually given, in terms of brand name, active ingredient, and what its purpose is. So, you know, it would just be nice, if either the time was taken for the nurse to take you through that, and actually write the instructions down in front of you and make sure that they’re correct. Or, that they’ve got a form where it is correct and it hasn’t had to be corrected.

They gave me the bag and the list. And I believe they talked through the list. And to be to be fair, I’ve actually got the list in front of me here and I’ve got the information - but certainly specifically about this particular medication in the capsule, it wasn’t made clear. And because of the various complications that arose, I went back into the hospital and I raised this, I said, “I’m going to run out of this", and it was only at that point it was explained to me that this is how you use these medicines.

And it's a classic communication problem. And it's also a classic problem of somebody who is dealing with this day in day out, they are very, very familiar with medications, and it is often the case that they just fail to appreciate that people who are having their first x surgery that it's a new experience and there's quite a lot to take in. And I, I feel that certainly there should be rather more attention and care paid to the instructions, particularly when you're not just on one tablet or whatever but you're on a cocktail of different medications that that have different functions post-surgery.

It felt incredibly rushed. The whole process felt rushed. That was one of the problems, it felt like you were on a production line and, you know, the sooner they could get you out of the recovery ward, the better. It's the lack of communication I think, the lack of understanding that for some people it's the first time they will have undergone surgery, and they're not familiar in the way that, you know, nursing staff would be very familiar with the standard medications. It, it's that thing of, "Well, I know it, why doesn't the patient know it?"

It's not just what to take and how the packaging works but it's also just some little tips. And again, it's those little things that probably when you're under pressure of time, and I do understand the pressures that the hospital is under, certainly post-COVID. Like they were trying to catch up and shorten the list as quickly as they possibly could. But in my case, I just feel that possibly a little more time spent in the first place would have saved several consultations, which I had to go in for afterwards, because of the problems that I was experiencing.

Story 4.

interface between hospital pharmacy and pharmacy sub-contractor for new medication procedure following discharge. This patient has experience of long term medication, and overall it works smoothly, but wanted to share the following insights:

I have quite a lot of experience, in fact, an awful lot of experience of hospitals, because of the nature of my health. And I would say 90%, probably more than that, 90% of time, the discharge is very good with regards to medicines. Most of the wards I'm on have their own pharmacist who comes round when you're admitted and goes through your medication, checks out, what you take in and organises the dosages while you're in hospital. And when you discharge, they come around again, and go through it. So, I would say the normal or sort of the routine, medication is handled very well.

In my experience, the only downside is if you're on any medication that requires you to have a prescription for some more, if it's a *new* medication, you know, apart from the one I'm going to go on to, you can be sat about literally for hours waiting for it to come up from the main pharmacy. The number of patients who were in, were literally waiting hours - when I say hours - like five or six hours just for the medication to come up. And they won't allow you to go down and collect it yourself. You know, so that can be very frustrating.

I suppose (my experience) would all stem around the use of *new procedures* involving the medication. I think they could have explained it a bit better. And they just kept referring to it. And in the end, I had my phone with me. So I looked it up on Google, you know, and sort of checked it out from that. No one actually came around and sat by me and said, "Well, this is what it is, this is how you use it. And this is why you use it". If I had shouted it, I think they may well have come and gone through it with me. And I sort of read it I thought, "Ah right, yeah, I see what's asked for" … it would have been better if someone had either gone through it with me in the hospital or when I got home somebody from (pharmacy medical device sub-contractor), instead of waiting two weeks for somebody to phone me. It would have been better if somebody phoned me the next day and say, "oh, yeah, we know you've just been discharged", and you go on. A fact sheet would have helped, I don't think they had anything like that. It would have helped I think if there was if somebody had come out and said, "that's what it recommended and just read that and it tells you all about it".

Once I got home, they said, "Oh, well (the pharmacy sub-contractor lead) will contact you. And they will send somebody to train you how do it". Well, they didn't, and I had to chase them. And basically without going into detail it took about two weeks to get the medication.

It is quite a specialist thing. And I guess this is, this is just an example of where the system can potentially, not break down, but not work as efficiently, when the pharmacy within the hospital is doing everything, they're, you know, they're in control of everything, but when they're relying on an outside company, you are just one of 1000s. And you know, the hospital has to issue a prescription to the exterior company - that can be problematic occasionally because pharmacist in the hospital may be under pressure, and they don't always do it when they're supposed to do it.

In this case, the (hospital pharmacist) *had* done it. But (pharmacy sub-contractor) hadn't seen it. And then that was part of the delay that the (hospital pharmacist) proved that they sent it in time. But (sub-contractor) hadn't acknowledged it. And when they investigated it, they said, "Oh, yeah, we did receive the prescription, but we overlooked it". So, as I say, it, works very well, most of the time, but that's when it can go wrong, is because of this interface between what the NHS controls within our hospital, and what they rely on an external third party to do, who is a commercial operation.

When you deal with a company like x, you have a coordinator, who is your personal contact. And I got a person called x who is very good, they always respond quite quickly and nine times out of 10 sort stuff out. They were the one that was telling me hospital hadn't issued a prescription because they were talking internally to the internal (company) pharmacists and the internal pharmacists were saying "we haven't received the prescription".

I was then going back to the department at the hospital and saying, "you haven't issued a prescription". And I had the hospital pharmacists phone me up, they said "you know, I've done it. I know I've done it" So, that's when the hospital pharmacists started talking to the (company) pharmacist. So, it was like a three-way conversation and me a piggy in the middle because one lot was telling me one thing and the other was telling me something else. And in the end, I did say, "Look, I'm piggy in the middle, you're telling me two different things? What's going on?"

Now, I'm pretty with it. I think if anybody was not as experienced as me, and may be new to the treatment, or a bit elderly, or a learning difficulty or whatever…I don't know what would happen then. Because they probably wouldn't have the wherewithal to know how the system works and who was doing what, because I know who's doing what I know, right off go to that one or that one. But I think, you know, I can get things sorted, whereas other people will or perhaps aren't as fortunate and haven't got the experience that I got, would have probably struggled, and it might have taken a while to resolve.

I am very grateful for all the treatment support I get from the hospital. In no way am I trying to give the impression that this was a huge issue. I've been championing NHS whenever I can – it's still something we should cherish.

I suppose it would have helped to say - there (needed to be) a bit more liaison and laying the ground rules down prior to discharge.

Story 5. Patient friendly communication

I have no intention to be critical as everyone was lovely, and had genuine desire to help, but if I can help them improve things for the next person…

I was in the hospital for surgery as part of ongoing treatment, so I am having a lot of hospital visits and have been for the last eighteen months or so, but this was the first time I had been in hospital overnight. So that was a new experience of me, so I was there for four nights…went in early on (weekday) and was discharged late afternoon on a weekend.

I think it was a nurse who was doing the discharge, who turned up with a big bag of medicines, I think they did sort of explain, but when I sat down and read the paperwork, I was not sure how long I was meant to take one of these for, as the paperwork doesn't tell you that. Some things it does say "stop when you don't need it", but this one it didn't say, so I did ask at the nurses" station…so yes, they supplied me with this carrier bag full of stuff and then I realised they hadn't given me the sharps bin promised, so I queried that, and they found that. I wouldn't say that they sat down and talked me through it in detail, it was a bit more "here it is" … not in a nasty way, but there wasn't a lot of conversation…

I live on my own which feels a little bit relevant, in that (in my job), I am good at reading and processing information, switched on, good at looking after myself - but there wasn't someone who could organise my medication for me (when I got home). So part of my thought was "I am quite well equipped to deal with this sort of stuff", I am less phased by this than some people might be, and other people might be less sure, and "if *I* am finding it difficult, goodness me! how much harder must it be for people who are in a more vulnerable situation?"

Whilst in the hospital, what happened many times a day, someone turned up and said "take these" basically, and they were very good about explaining what it was and why I was taking it, which I like, as I want to know what it is for. So I went from that level (in hospital) "here is a little pot and take one of these now" to (when I went home) "here's a carrier bag, of assorted liquid tablets, injections, and here is a piece of paper that explains what to do".

And it just wasn't organised - it was organised like for a medical person who might need to know what you were taking, and it's really good to have that, as when the pharmacist at the GP surgery wanted to do a medication review, I had a list … but actually for a *human being* taking these, what you really need to know is "at breakfast time take these ones and at lunchtime take those ones". I like to organise data, and this data could have been presented in a more human friendly way, a more patient friendly way….

A friend drove me home (on discharge), and made sure I was happy and then left, but it was just that feeling of being really overwhelmed, I was just home, I had (medical equipment) in at that point, moving around was difficult, I was in pain, I was trying to figure out what I could and couldn't do physically in my house, I was trying to work out how I would feed my cats, and myself.

Oh my goodness, I knew I had to sit down and read this page and a half of medications, because it was about to be dinner time and I knew I needed to take some tablets and I didn't know which ones it was. In the grand scheme of things, it was fine, but it was quite overwhelming, to actually just do all of those things and yes, the thought of somebody more vulnerable having to do it, my goodness if I was feeling fragile enough, at that point it must be so much worse for other people. I just thought "what I need is a list which says "take these at breakfast" "take these at lunch" I wrote myself a list and I put it on my phone, so I could copy and paste it for each day and cross off the ones I had taken, but yes, they could have given me that list in a more helpful way.

When I came home the pain wasn't too bad, so I took the slightly scary opiate, not the awful looking scary opiate, and then 3 days later at 3 o'clock in the morning, I have no words to describe the pain, and its 3 a.m., it's like, "what am I supposed to do?" and I spent some time looking at whether to break open this bottle and thinking "it must be ok as they have given it to me" despite the scary warning on the box, and I did take it. I did wonder about calling NHS 111 at that point, but I was unsure whether they would be able to help with that kind of thing, and I did have this bottle … In the hospital they were giving it in a little syringe which they measured it out and tablets in a little pot, and squirt this foul tasting stuff in your mouth. But I opened this box and found nothing, and thought "oh yes, when I was little, my parents had this little white spoon" oh, ok, I don't have medication spoons in my house, and it's 3 a.m. in really quite a lot of pain, trying to find the spoon and to work out which is the right one…I don't recommend it as a life experience. I then discovered I had no way of measuring out the quantity, I was supposed to be taking.

I didn't know the medicines helpline existed until I saw this survey….looking now at my notes …on the medicines discharge list…page 2, page 3, right at the end it says, "if you have any questions please ring the patient helpline" there we go - I just didn't see it…looking at it now, it runs Monday to Friday, which is great, and I understand staffing, but I got home on a weekend evening, so some questions would have waited til the helpline and some wouldn't…I guess.

It would have been really helpful to be able to ring the medicines helpline and say "I have got all these medications which have large alarming warnings about addiction (opiates for pain), how scared should I be?", as I was really scared, I was really reluctant to take them, when the label said "may cause addiction" and I had heard about this, and it was really scary, so if there had been someone I could ring who could say "no, its fine, take it, a week is ok" that would have been great, very reassuring.

One easy thing that would make a huge difference, that means a lot to me, when it worked and that is relatively easy, is that people call me by my *right name*….as my paperwork has Margaret* and I am technically this, but I am Maggie in real life

Literally everyone calls me Maggie…so on the ward some of the medical staff were great and called me this, but every time I meet a new medical person they call me Margaret, and every time I get a letter they call me Margaret, which on some level is ok, it really doesn't matter, but do you know, it would be easy and so nice if there was a box somewhere you could tick and say "please call me Maggie" … I feel, it's not rocket science, I feel like saying "this is the name I would like you to call me regardless of the paperwork" I feel that this is not difficult to achieve and it's so nice when someone calls me by what is my name … Margaret is the patient version of me and Maggie is *me!*

(* N.B. Name has been changed)

Story 6. Communication - “spelling it out”

There’s a bit of you that wants to get out, get home.

But there’s bits of you that doesn’t really want to rush the process because you know, that when you’ve got a hospital full of people around you, trained to help you, if you have any things go wrong, you know, if it suddenly comes to mind, you have somebody to ask.

When you’re away from that support structure, so there is a slight nervousness about stepping away from the support.

Clarity or judgement, depending on the level of pain, can obviously influence your ability to think and take things in. And the converse is that the process of reducing pain can fog your mind … if some (medication) is, say, “four times a day”, (and they always put this sort of thing on the side), you know, “take as indicated by your doctor” or something along those lines… that’s when you would get worried, because you think, “ah, was that before meals, with meals or after meals?”

If for example, it says “take three times a day”, when you’re talking to pharmacists, and in five minutes, they’re gone … talking to the next patient. And in 10 minutes, I’m out the door. It’s only on the way home, I think “oh, was that with meals, after meals?” That’s what I mean is by giving them that extra bit of time to do stuff.

I think it really spelling out very clearly what the doctor’s instruction is rather than the packets” instruction. That’s where having it spelled out, is good.

It could simply be down to saying “We will spell it out, totally clear. This is before a meal. This is with a meal …” So, there’s no question, because what a doctor may recommend could be different to what’s on the leaflet. Some leaflets are in huge detail, others less so. And there may be a reason why it’s different to what’s on the leaflet.

You could design a form that you could print out on A4… “What’s the medication? And how is it to be taken? Things that you mustn’t do?” So those are the sorts of things where it would be helpful.

You don’t necessarily know the care situation for people at home. You take somebody who’s going back (home) where the person who’s dealing with (them) is actually the carer of other people, they have a parent or a grandparent, or they’ve got a sick husband or wife. And people don’t always tell you, because they don’t want to make a fuss. You don’t know who the patient’s carer is … that patient’s carer, especially for older people, could be another even older person who’s got problems with their eyesight, who may have had something similar,

similar sounding. And then (they say) “no, no this is what you do”. And they’re doing their best, but they get it wrong.

So having it nice and clear. In nice clear print. They can read it and you’re just basically setting a level of language, “take one tablet”, take one patient … connect the two, you know what I’m saying… but just spelling it out very clearly.

And the staff are brilliant, the care and compassion of the staff was phenomenal. They work long hours, they’ve got the added pressures of COVID. Not in their professional environment, but also in their personal environment. And yet, they still come in and do a great job. And at the end of it, they’re still doing a great job when they walk out the door. And I think that, that takes a heck of a lot. I mean, some of its training, but a lot of these just mindset, and the fact that they’re really good people.

11. Appendix

Appendix 1: Leaving hospital with medicines further information

Both the NHS and individual hospital trusts offer additional support for patients around medication. On return home following a hospital stay patients may be offered in-house support via:

- A **Patient Medicines Helpline** – dedicated phone line open to all patients leaving hospital to contact hospital pharmacist for follow up support and advice on taking their medicines

Or where eligible, be referred for additional support via services commissioned from Community Pharmacies:

- **Discharge Medicines Service (DMS)** – where more complex cases are referred direct to a community pharmacy for support with medications
- **New Medicines Service (NMS)**– referring patients who are taking medicines for the first time for a long-term condition to a community pharmacist

The GP, or GP based pharmacist will provide regular and ongoing medication and medication review.

Patient Medicines Helpline

Oxford University Hospitals NHS Foundation Trust established the Patient Medicines Helpline ten years ago, accessed by people who are discharged with medications from an OUHT hospital (i.e. from John Radcliffe, Nuffield Orthopaedic, Horton or Churchill). The line is fully staffed by a Lead Pharmacist and accredited pharmacist technicians. The aim of the Helpline is to enable people discharged from hospital with medications to speak directly to a pharmacist/ accredited pharmacist technician via a single point of contact, for advice, support, and information on using this medication or any questions or concerns. They can do this via phone or email. The service is available to anyone in the region discharged from an OUHT hospital.

During Covid-19 this service was also made available for people with concerns and questions about vaccines via the vaccine centres and GPs.

The Helpline is open from Monday to Friday 9.00am - 5.00pm and calls are at local cost.
(Between 1.00pm and 2.00pm calls are diverted to a voicemail service). There is ability to request an interpreter, but this has to be booked in advance.

People are able to ask questions such as:

- How should I take a newly started medicine?
- Can I take other medicines at the same time?
- Do certain foods affect my medicine/s?
- Could a new symptom be a side effect of a medicine?

The helpline service is promoted on OUHT website (https://www.ouh.nhs.uk/services/departments/pharmacy/helpline.aspx), and via health professionals, posters and leaflets. It is highlighted via information given to patients on discharge, on the Discharge Letter and at outpatients following visits to specialists, and by posters in GP and vaccine centres.

Call numbers have remained consistent over the years. Anecdotally most making use of this service speak fluent English. Staff spoken to were "not aware" of take up of interpreting offer to date, commenting "occasionally family members have interpreted".

Year	**Helpline calls per year (source OUHT)**
2017	634
2018	572
2019	616
2020	647
2021	1957 calls (N.B. includes additional COVID-19 vaccine calls from members of the general public)

Oxford University Hospitals Patient Medicines Helpline call numbers 2017-21 (Source OUHT)

NHS Discharge Medicines Service

Patients needing more complex medicines support may be identified by the hospital pharmacist and referred electronically to a community pharmacist for follow up support with medications after hospital via the *NHS Discharge Medicines Service*. Examples of patients needing this type of support include those taking high-risk medicines, those who have had changes made to their medicines regime while in hospital and those who have been prescribed new medicines.

This service “was established as a new essential service for community pharmacy contractors, on 15 February 2021. As an essential service, it must be provided by all community pharmacy contractors.

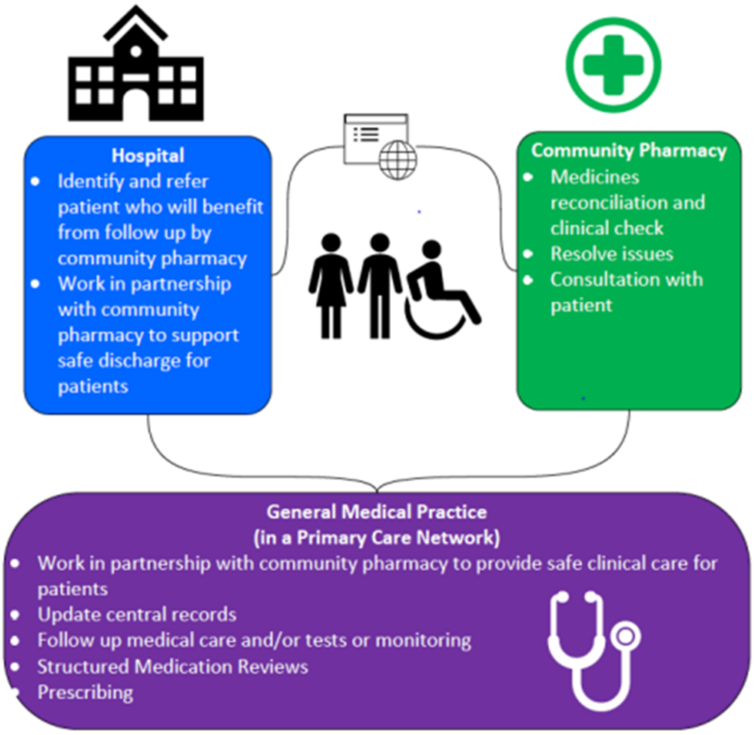
The service was established to ensure better communication of changes to a patient’s medication when they leave hospital and to reduce incidences of avoidable harm caused by medicines. By referring patients to community pharmacy on discharge with information about medication changes made in hospital, community pharmacy can support patients to improve outcomes, prevent harm and reduce readmissions”. (See: https://www.england.nhs.uk/primary-care/pharmacy/nhs-discharge-medicines-service/)

A *Community Pharmacy Contractual Framework* sets out clearly the expectations of the community pharmacy contractor when receiving a discharge referral, including when they should involve PCN pharmacy teams and NHS trusts.

Where new medicines have been commenced, the community pharmacist may also be able to provide further support via other commissioned services, such as the New Medicines Service, where this would be clinically appropriate and where the patient meets the eligibility criteria”

Discharge from hospital is associated with increased risk of avoidable medication related harm. The NICE guideline NG056 (https://www.nice.org.uk/guidance/QS120/chapter/Quality-statement-5-Medicines-reconciliation-in-primary-care) included the following recommendations: a) Medicines-related communication systems should be in place when patients move from one care setting to another. b) Medicines reconciliation processes should be in place for all persons discharged from a hospital or another care setting back into primary care and the act of reconciling the medicines should happen within a week of the patient being discharged. Implementation of these recommendations requires pharmacy professionals and their teams across hospitals, primary care networks (PCNs) and community pharmacy to work together much more effectively”. (Source:

Figure 3.1: NHS Discharge Medicines Service patient pathway



Hospital

- Identify and refer patient who will benefit from follow up by community pharmacy
- Work in partnership with community pharmacy to support safe discharge for patients

Community Pharmacy

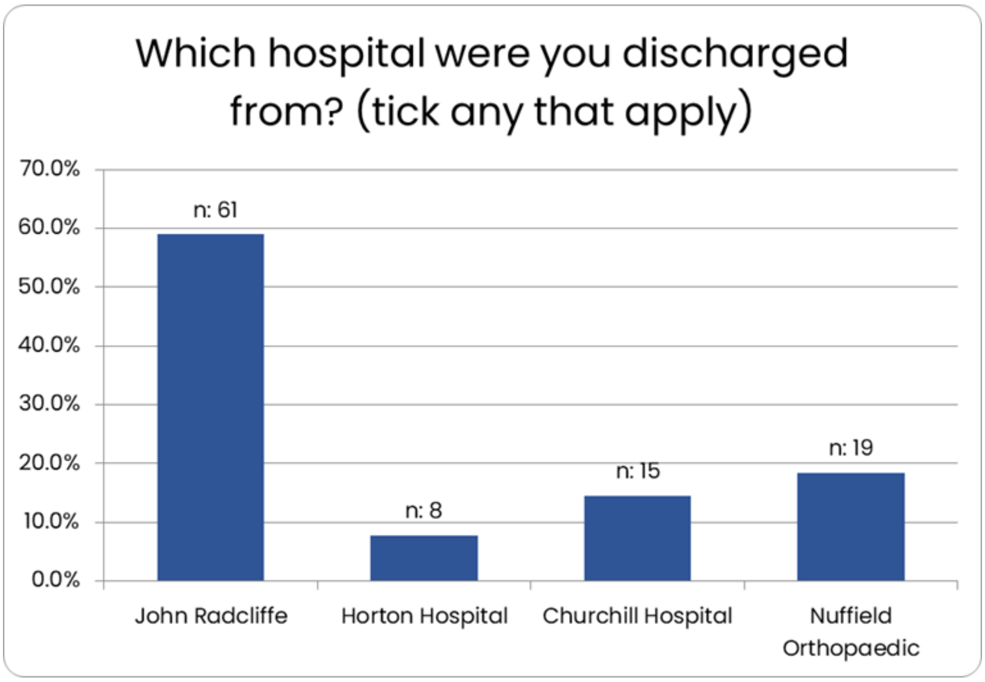
- Medicines reconciliation and clinical check
- Resolve issues
- Consultation with patient

General Medical Practice (in a Primary Care Network)

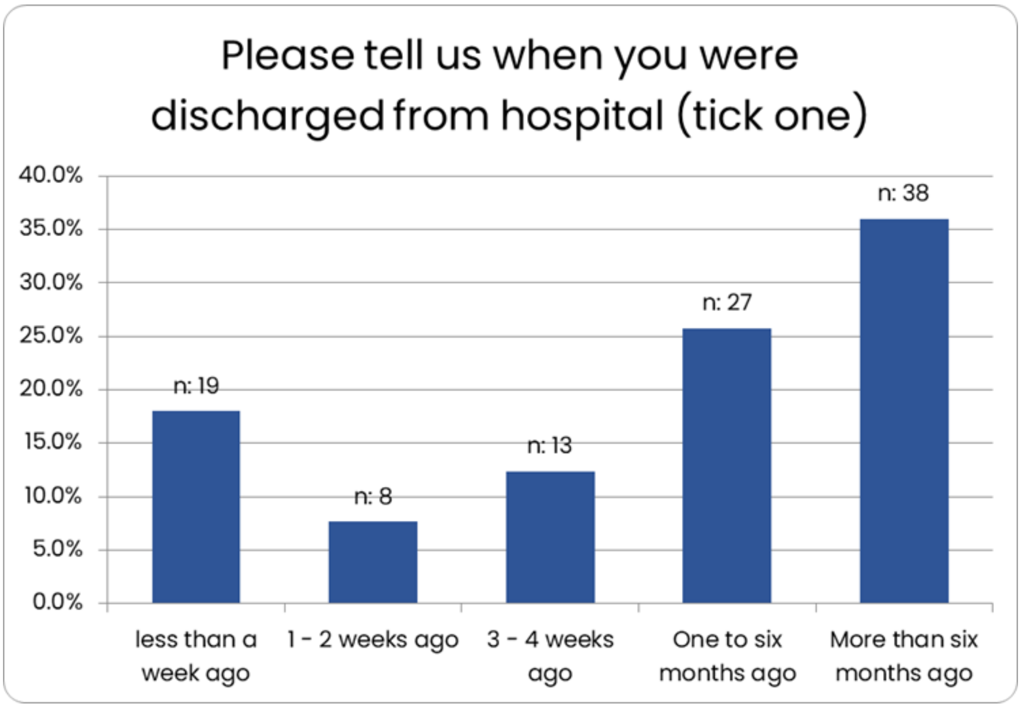
- Work in partnership with community pharmacy to provide safe clinical care for patients
- Update central records
- Follow up medical care and/or tests or monitoring
- Structured Medication Reviews
- Prescribing

(See source: https://psnc.org.uk/national-pharmacy-services/essential-services/discharge-medicines-service/)

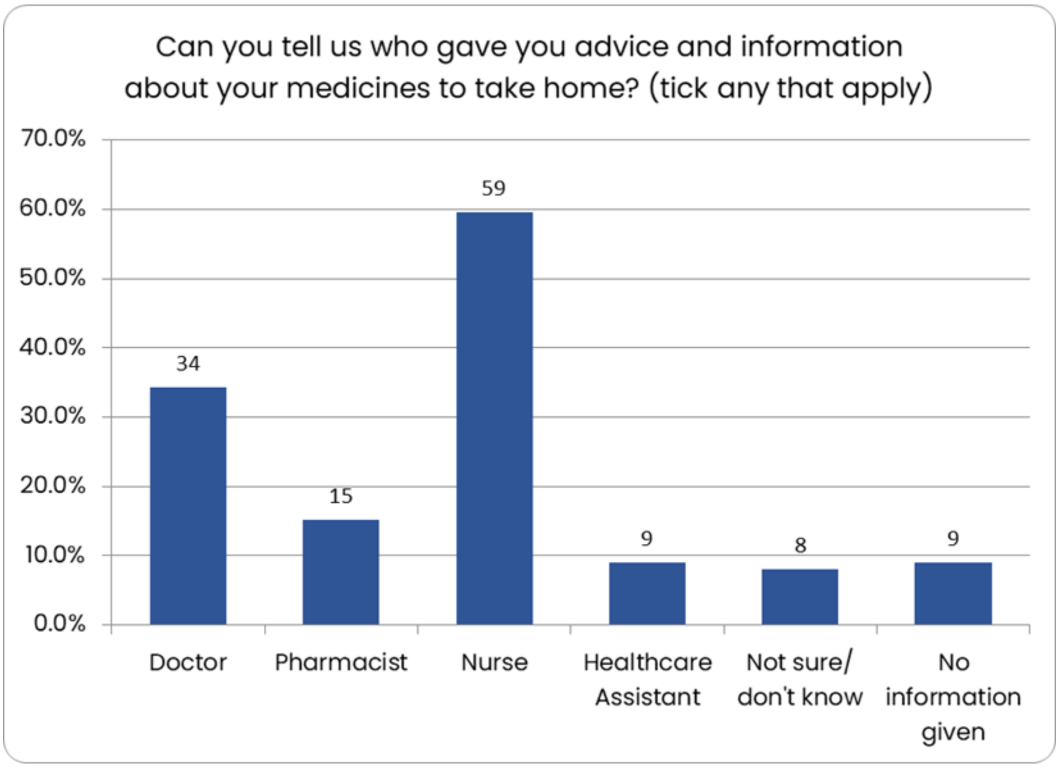
Appendix 2: Data summary from online survey responses



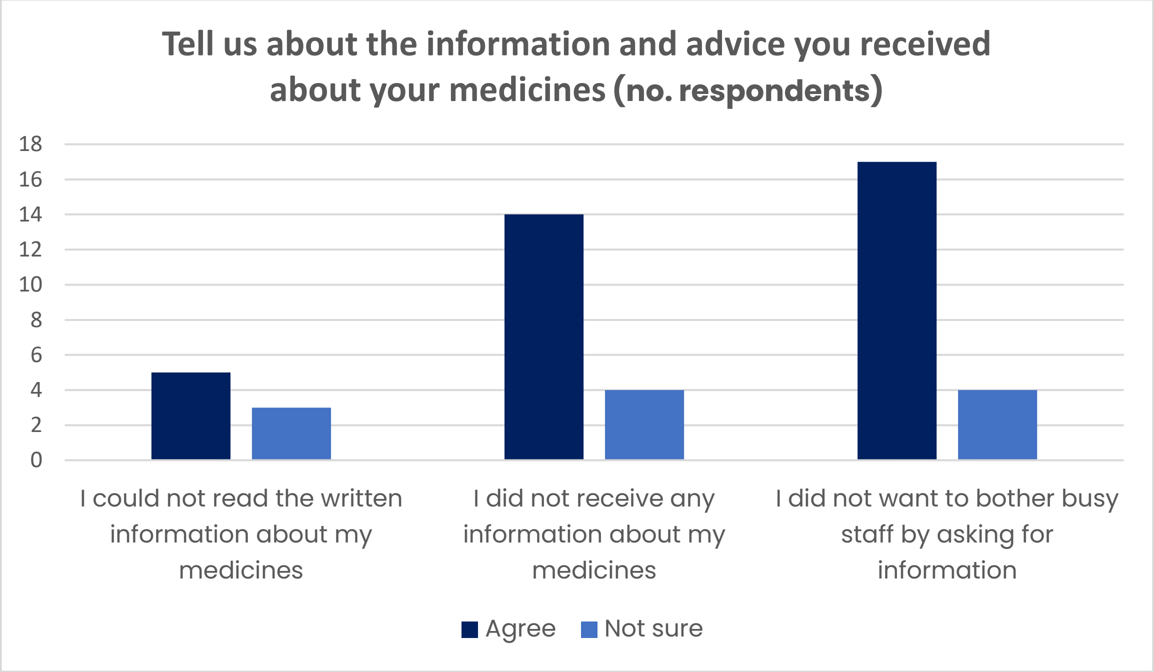
(103 responses)



(105 respondents)



(99 respondents)



(47 responses)

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Discharge Medicines Service (DMS) https://psnc.org.uk/national-pharmacy-services/essential-services/discharge-medicines-service/

New Medicines Service (NMS) https://psnc.org.uk/national-pharmacy-services/advanced-services/nms/

Wills, S., (2014). Who do discharged patients call if they have medication queries? *Clinical Pharmacist*, 6(4), pp.103-4. (Outlining Thames Valley and Wessex development of a standard for medicine helplines)

The UKMI Patient helpline audit standards: https://www.sps.nhs.uk/wp-content/uploads/2017/01/MedicinesHelplineStandardsvn3_2.pdf

Guide to implementing helpline for hospital patients and the user survey: https://www.sps.nhs.uk/wp-content/uploads/2017/01/ImplementingaMedicinesHelplinevn14.pdf

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